# Signifying Zika: heterogeneity in the representations of the virus by history of infection

Dando significado ao vírus Zika: heterogeneidade nas representações sociais do vírus de acordo com a história de infecção

Dando significado al virus Zika: heterogeneidad en las representaciones del virus por el historial de infección

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# Abstract

Despite having been broadly advertised by the mass media, many negative consequences of the Zika virus have been less significant than originally predicted. It is likely that after a few months from the epidemic's onset, personal experience with the virus has altered the person's way to deal with the disease. This study explores the relation between exposure to Zika virus and the social representation of the epidemic. More specifically, one analyzes if increased exposure to the risk of Zika infection changes the characteristics of the web of meanings surrounding the epidemic. Between August and November of 2016, 150 interviews were conducted in the municipality of Governador Valadares, Minas Gerais State, Brazil. Based on the Free Words Association Technique, data on evocations related to the Zika virus were modeled by social network analysis, allowing the characterization of the web of meanings by level of exposure to the risk of Zika infection. The analysis performed here suggests that those never infected by any disease transmitted by the Aedes aegypti mosquito have a lesser representation, incorporating information from the media through lay thinking. In contrast to those with low levels of exposure, the social representation of people infected by Zika is associated with meanings related to the most common symptoms, such as pain, rash, and itching. Personal experience seems to shape the social representation of the disease, increasing the focus on its proximate consequences. Public campaigns designed to foster protective behavior should take into consideration the heterogeneity in the representations of this epidemic to improve adherence to preventive behavior.

Zika Virus; Risk-Taking; Social Support

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# Introduction

In late 2015, Zika was making its first cases in the Americas. Although transmitted by the same vector as Dengue and Chikungunya, Zika was gaining attention in the news due to its most alarming consequence: microcephaly, a type of congenital Zika syndrome. The media concentrated its coverage on babies born with small head circumference and a stranded future. The fear of large-scale consequences for a whole generation led authorities to recommend postponing pregnancy and reinforcing the measures of vector elimination that were already in place for dengue <sup>1,2</sup>.

The intense broadcast of images showing babies born with microcephaly caused social turmoil and a sense of collective vulnerability. In these initial months of the epidemic, there was uncertainty about causes, consequences and potential for spread, making it difficult for the public to understand this new and quickly evolving public health threat. Despite the dramatic coverage Zika has been given, little is still known about how people are interpreting the disease, particularly whether they understand it as a real threat, how they make sense of their own vulnerability and whether they are putting knowledge into action.

This study examines how individuals collectively signify the Zika virus (ZIKV) epidemic. Based on the idea that personal involvement influences and shapes the representation of diseases <sup>3</sup>, we hypothesize that the meanings people give to what they see or hear during the outbreak are subjected to their own experiences with the virus. We call web of meanings the interaction between the meanings surrounding ZIKV atributed by individuals who share the same social context. Individuals infected with ZIKV, Dengue, or Chikungunya might see the disease differently from those whose contact with these viruses is solely through the news or public health campaigns. We perform a social network analysis using novel data on individuals' evocations regarding the ZIKV collected in a municipality that's a hotspot for Dengue in Brazil. We look at three different histories of self-reported infection: those never infected by any of the diseases transmitted by the *Aedes aegypti* mosquito; those that have been infected by Dengue or Chikungunya, but not by ZIKV, and those previously infected by ZIKV. This is a first step in disentangling the different ways individuals attribute collective meanings to ZIKV as the outbreak unfolds. The analysis will equip policymakers with information on social thinking, a necessary tool for effective public health campaigns targeted at behavioral change towards preventive behavior against the ZIKV threat and its socioeconomic, health and reproductive consequences.

# The ZIKV epidemic: roots, diffusion and social behavior during the outbreak

In Brazil, ZIKV was first recorded in early 2015 and the epidemic rapidly gained momentum. In May 2015, the Pan American Health Organization (PAHO) announced the first confirmed case of infection <sup>4</sup>. In February 2016, ZIKV became a disease of mandatory notification in Brazil. Since the beginning of the infection until the most recent epidemiological report in 2017 (epidemiological week 15) 223,230 cases have been reported, distributed across over 2,000 municipalities with 133,527 confirmed cases. In 2016, ZIKV's incidence rate was 105.3 cases per each 100,000 inhabitants <sup>5</sup>.

Considering that Dengue's infection rates are even higher and both diseases are transmitted by the same vector, ZIKV's potential for spreading is enormous. Data from the epidemiological week 52 of 2016, for example, shows that Dengue's incidence was as high as 733.4 in Brazil <sup>5</sup>. One challenge public officials and epidemiologists face when estimating ZIKV epidemic dimension is that as much as 80% of infections are symptomless, increasing the potential for underreport. Furthermore, despite symptoms specific to ZIKV (like rash with itch, joint pain/swelling, and conjunctivitis), others are similar to Dengue (fever, headache, muscle pain and rash) <sup>1,6,7</sup>.

The ZIKV epidemic put Brazil in the epicenter of international attention and media coverage <sup>8</sup>. Concerns are centered around its most dangerous consequence, microcephaly – an illness that affects the fetus of infected mothers and that is one of the possible outcomes of what is now called congenital Zika syndrome <sup>2,9,10</sup>. In 2016, 2,653 cases of microcephaly or alterations of the central nervous system were confirmed in Brazil <sup>11</sup>. ZIKV can also lead to developmental, neurological and ophthalmological problems even if a fetus does not develop microcephaly <sup>8,12</sup>.

ZIKV is also transmitted via sexual intercourse, blood transfusions and amniotic fluid <sup>12,13,14</sup>, requiring protective strategies in addition to mosquito vector elimination. Behavioral changes are the

only way to slow down sexual transmission <sup>15</sup>, making it imperative that researchers discover how individuals change their behavior in response to the epidemic. Several examples in the epidemiological and social literature regarding social perception and behavior during epidemic are elucidative. A study found that during the H1N1 flu outbreak in 2009, changing behavior was associated with perceptions that the swine flu was severe, that the risk of infection was high and that the outbreak would last for a long time <sup>16</sup>. Respondents who reported that the outbreak was "over-hyped" were less likely to demonstrate any change in behavior – a potential scenario for persistent spread. Focusing on the SARS (severe acute respiratory syndrome) epidemic in Hong Kong, another study showed that although the perceived chance of infection was low (9%), the fear of infection was high (48%) and, possibly due to the campaigns, people learned how to efficiently employ measures of protection over time <sup>17</sup>.

One key factor associated with changes in social representation is personal involvement. Rouquette <sup>18</sup> describes that the amount of personal involvement will vary according to the evaluation of risk of infection, the personal exposure to risk and the perceived capacity to act towards it. The higher the three factors, the higher the involvement. Thus, a change in personal involvement triggers a change in some of the aspects of its social representation <sup>18</sup> and therefore the understanding of a social phenomenon. As such, the social perception of health threats like ZIKV are likely sensitive to the degree of exposure and involvement, triggering different coping mechanisms and behavioral responses <sup>3,19</sup>. For this reason, finding out the meanings individuals give to infections, their risk perceptions, and whether they differ according to personal experience, particularly for emerging threats for which individual behaviors towards them are largely unknown, is an important instrument for more effective public health communications and for the promotion of protective behavior amidst these epidemic.

#### Methods

This study used novel data on mental representations of ZIKV for urban residents of Governador Valadares, Minas Gerais State, Brazil. The choice for Governador Valadares is justified because the city ranks third in the state for the LIRAa index (Assessment of *Aedes aegypti* Infestation Index), and is classified in the very high incidence cluster for Dengue in Brazil <sup>20</sup>. The 2017 LIRAa for Governador Valadares was 8.5%, above the minimum threshold of 3.9% for the high risk category <sup>21</sup>. In 2016 alone, 1,609 cases of Dengue, 115 of Chikungunya, and 3,154 of ZIKV were reported in Governador Valadares. Key for our study, the city was also hit by contaminated mud from the Samarco dam failure in November 2015 <sup>22</sup>. This unprecedented incident created severe water shortages due to the contamination of the city's main river by heavy metals, leading residents to stock water at home. Such massive amounts of stocked water contributed to the proliferation of the *A. aegypti* in the region, making the city a key social context to understand ZIKV's social representation.

The selection of respondents was based on a baseline probabilistic survey conducted from January 2014 to June 2016 with 1,226 individuals. The baseline survey is part of the research project Migration, Vulnerability, and Environmental Change in the Rio Doce Valley. For the present study, we aimed at collecting 150 respondents (Table 1, Panel A) using the following procedure. We first randomized the 1,226 baseline interviews and separated them into four groups (female high socioeconomic status; female low socioeconomic status; male high socioeconomic status; male low socioeconomic status). The socioeconomic status assignment was based on a standardized social class scale proposed by the Brazilian Association of Research Companies <sup>23</sup>. We then contacted the first candidate of each group by phone as s/he appeared in the random sequence in order to fill a stratified sample of 50 respondents in each category of infection (past/current ZIKV infection, past/current Dengue or Chikungunya infection but not ZIKV, never infected with any A. aegypti transmitted disease). Due to ZIKV's rarity, it was not possible to fulfill all quotas with the available baseline sample and we ended up with only 117 cases, which is our analytical sample (Table 1, Panel B). Infection was based on self-reported answers <sup>24</sup>. Post-survey weight adjustments were performed based on Dengue, Chikungunya, and ZIKV incidence in Governador Valadares to balance the group's sizes and avoid biased links between evocations by history of infection.

#### Table 1

Distribution of interviews by gender, socioeconomic status, and level of exposure to the Zika virus. Governador Valadares, Minas Gerais State, Brazil, 2016.

Gender/Socioeconomic status		Level of exposure			Total
	No disease	Dengue or Chikungunya	Zika	Missing	
Panel A: original sample design (balanced)					
Female					
Low	13	13	13	0	39
High	12	12	12	0	36
Male					
Low	12	12	12	0	36
High	13	13	13	0	39
Total	50	50	50	0	150
Panel B: actual sample (unbalanced)					
Female					
Low	16	4	0	1	21
High	28	8	3	0	39
Male					
Low	16	7	10	0	33
High	14	6	3	1	24
Total	74	25	16	2	117

Source: author's elaboration based on primary survey data (Research project: *Migration, Vulnerability, and Environmental Changes in the Doce River Valley, 2013-2016*).

Although information on infection was self-reported, we performed an initial screening to reduce potential bias. During the first phone contact, respondents were asked how they knew if they were infected or not by Dengue, Chikungunya, or ZIKV. We started by letting them freely suggest the diagnostic criterion. In all cases of self-diagnosis, the phone call contact was interrupted and a new call was made to the next pearson appearing in the list of random numbers from the baseline survey. This procedure was repeated until we found a person whose diagnosis had been made by a health professional. For those who said s/he was diagnosed by a health professional, we further asked if they had taken a serological test for detection or if the health professional clinically diagnosed him/her.

The questionnaire used in this study comprises of two modules: one for the collection of data on representations of the ZIKV and another on personal involvement with the disease. Based on the Free Words Association Technique <sup>25</sup>, the first module contains the following questions: (1) "When I say 'ZIKA VIRUS' tell me the first five words or expressions that come into your mind, without thinking about them"; (2) "Now, I would like you to put them in order of importance for you, 1 meaning the most and 5 the least important"; (3) "You mentioned that expression 'FILL IN' was the most important for you. What does it mean to you? [Open question]"; (4) "Why is it the most important to you?".

The second module contains basic information regarding whether respondents had been previously diagnosed by a health professional with each of the three main diseases, the type of diagnostic (clinical or serological), time since diagnosed and if any member in the household or close friend were diagnosed with any of the diseases.

Evocations were coded according to their meaning, a procedure described elsewhere (see Supplementary Material for details on coding: http://cadernos.ensp.fiocruz.br/csp/public\_site/arquivo/ supplementary-material-to-the-manuscript\_4890.pdf)<sup>26</sup>. Although 240 unique words or expressions were used, their grouping into common concepts resulted in 66 categories of meanings. We applied inductive reasoning when defining preliminary codes to reflect the participant's meanings. These codes reduced the amount of variation without losing each usage's unique meaning. When the word was too vague for proper classification, the researcher read the answers to question 3 searching for an explanation that would satisfy the meaning given to the vague word. In cases when it did not fit a pre-defined code, a new code would be created.

These coded evocations were modeled using social network analysis <sup>27</sup>. Other proposed techniques for this type of data <sup>25,28</sup> lack the ability to fully quantify topological characteristics of the web of meanings, such as the centrality of certain evocations and the density of the total network and its communities. Furthermore, identification of subgroups of individuals based on their shared meanings is arbitrary in other techniques, while validated through simulation within the network analysis framework <sup>29</sup>. We started by transforming the coded evocations into relational data using the R package wordevok we developed (The R Foundation for Statistical Computing, Vienna, Austria; http://www.r-project.org). The following assumptions were used to create data on linked evocations.

Assumption 1 [personal cognitive network]: evocations from the same individual j, vk(j), are mentally connected.

Since evocations gravitate around an inducting term, the likelihood of random responses is reduced. However, because people rank words by their perceived order of importance, this rank may provide information on their practical values <sup>3</sup>. The following assumptions account for that:

Assumption 2 [distance]: for the same individual j, any two evocations contained in the evocation vector V(j) are more important the closer they sit to each other.

Assumption 3 [order]: for the same individual j, any two evocations of equal distance are more important the higher the order of the origin evocation. Thus, for an edge formed by two evocations,  $v_{k(j)}$  and  $v_{z(j)}$ :  $w(e_{kz(j)} = v^{o_k(j)}, v^{o+1}_{z(j)}) > w(e_{kz(j)} = v^{o+1}_{k(j)}, v^{o+2}_{z(j)}) > ... > w(e_{kz(j)} = v^{o+q-1}_{k(j)}, v^{o+q}_{z(j)})$ , with  $v_{ok(j)}$  being the k-th vertex of the j-th individual of order o, and q the length of  $V_{(j)}$ .

Assumption 2 assures that two related evocations would have more significance the shorter the distance they have from each other. Assumption 3 assures that in addition to the distance, the order that the origin evocation is located matters for weighting purposes. If two evocations have the same distance (words 1 and 2 or words 4 and 5, for example), the edge with the highest order origin evocation would be assigned the largest weight. Although evocations are referred to as origin and destination, the network is still undirected.

To parametrize these weights we defined two parameters,  $\varpi$  and  $\rho$ , that penalize edges by distance and order, respectively. We propose a general formula to account for Assumptions 2 and 3. Parameters  $\rho$  and  $\theta$  are defined as  $\rho(i,h) = m - |i - h|$  and  $\theta(i,h) = 2^{2m+2-(i+h)} - 1$ . Both parameters are indexed on i and h – the rank of evocations within the evocation vector,  $V_{(j)}$ . The general formula for the edge weights is, then:

$$\vartheta (\rho, \theta, m, M) = \underbrace{\frac{\rho(i, h) * \theta(i, h)}{\sum_{i=1}^{m-1} \sum_{h=i+1}^{m} \rho(i, h) * \theta(i, h)}_{T} * \left[1 - \frac{(M-m)*(M-m+1)}{M*(M+1)}\right] \quad \text{for all } i \ge 1 \text{ and } i < h \le m$$
(1)

where the  $\tau$  factor corresponds to the normalized weight for each edge, and  $\omega$  represents a factor that penalizes each person's evocation vector by its length. Parameters m and M are the vector length related to the j-th individual and the largest vector in the sample, respectively.

When evocations are coded, loops are likely to occur. These loops, however, are not natural to the network structure, but induced by the coding process. Imagine the following evocation vector for the j-th person:  $V_{(j)} = \{Disease, Dengue, Mosquito, Aedes aegypti, Microcephaly\}$ . If coding produces the vector  $V_{s_{(j)}} = \{Disease, Dengue, Mosquito, Mosquito, Microcephaly\}$ , the edge  $e_v s^{s_3}_{Mosquito(j)}, v^{s_4}_{Mosquito(j)}$  represents an induced loop. To eliminate such loops, two strategies were used:

1. Reclassification of identical evocations for the same individual in the entire dataset, so they are represented differently.

2. When reclassification was not possible, the vertex of smaller order was dropped and the vertex set rearranged accordingly. For instance, if  $V_{s(j)} = \{v^{(so)}_{k(j)}, v^{(so+1)}_{z(j)}, v^{(so+2)}_{t(j)}, v^{(so+3)}_{x(j)}\}$ , it was redefined as  $V_{s(j)} = \{v^{(so)}_{k(j)}, v^{(so+1)}_{z(j)}, v^{(so+3)}_{x(j)}\}$ .

With the relational data in hand, the web of meanings regarding the ZIKV was decomposed using the algorithm proposed by Newman & Girvan <sup>29</sup>. This algorithm optimizes the modularity of a partition, comparing the observed network with a network with the same observed degree distribution but with edges placed at random. The decomposition was performed for the full sample and for each

history of infection (Figure 1) using software R 3.2.4 with the *igraph* package. Figures 1 and 2 were designed using software Gephi 0.9.1 (https://gephi.org/gephi/0.9.1/apidocs/index.html?overview-summary.html). Edges were weighted by Equation (1) and nodes size were based on the weighted betweenness centrality, which represents the ability of an evocation to centralize and regulate the flow of meanings that form ZIKV's collective representation. This measure was also used to describe the most important evocations in the network. In addition to this centrality measure, we provide the full list of evocations' weighted degrees by history of infection and diagnostic criterion as Supplementary Material (http://cadernos.ensp.fiocruz.br/csp/public\_site/arquivo/supplementary-material-to-the-manuscript\_4890.pdf).

#### Results

#### Heterogeneity in representations of the ZIKV

We start by describing the web of meanings formed by the full sample and by each history of infection, exploring the meanings given by respondents to the words with highest centrality (Figure 1). We then explore in more detail how these representations change among those infected with ZIKV as we consider different diagnostic criteria (Figure 2). This strategy was used to understand if those networks formed among individuals who were tested for the virus are more closely related to the infection described in medical literature (see Supplementary Material for details on a probabilistic model of cognitive affinity based on history of infection and diagnosis criterion: http://cadernos.ensp.fiocruz. br/csp/public\_site/arquivo/supplementary-material-to-the-manuscript\_4890.pdf).

#### Full network (density = 0.202; nodes = 69; edges = 475)

The complete series of evocations form a web of meaning (Figure 1) in which the most important word is "disease". When asked to define what disease means, most respondents focused on ZIKV as a transmissible disease, causing symptoms that are difficult to control. The second most central word is "pain", considered as the worst symptom. One respondent explains that "*it is an excruciating pain, almost unbearable. I felt very bad*". But this level of pain was also noticed by people who did not have ZIKV: "*I heard you cannot even get up of bed*", said one of our respondents. The third word, "lack of commitment", relates to the individuals' awareness about their lack of preventive actions (such as keeping their yards clear from mosquito breeding sites) and by local authorities' negligence who "could supervise and inspect" households.

The fourth word, "malaise", is another consistently mentioned symptom. The fifth and sixth words, "mosquito" and "fear", express the feeling of being infected and having to deal with either the symptoms or "getting pregnant and having a child with problems", given the surge of ZIKV that appeared in Governador Valadares during the months prior to this research. Fear also relates to the gravity of the disease, who noted that "it can kill", "it's difficult to prevent", "it's serious or else the media wouldn't be talking about it all the time", and "everybody is at risk".

"Something bad", the seventh expression, encompasses an array of words related to the epidemic (e.g. bad, horrible, discouraging), a superficial description that did not portray severity or chaos. The eighth word, "weakness", also represents a collection of symptoms related to the lethargy associated with the disease (e.g. tired, depressive, weak, only wants to lie down, sleepy). "Death", the ninth word, represents the worst possible consequence. Since cases of death by ZIKV are rather rare, we suspect that those who mention this level of severity are unfamiliar with the disease. "Microcephaly", the most broadcasted word by the media, appears only in the tenth position.

In sum, these ten most central words' meanings are very diverse and related to the threat posed by ZIKV, its potential for spread and the lack of commitment to make improvements that could stop its spread. Five sub-networks (clusters) of meanings emerge from inside the general network. We named these clusters after their latent meaning according to their words with highest centralities (Figure 1).

The first cluster, *lack of social and personal responsibility*, is mainly formed by the central words disease, mosquito, standing water, death, lack of prevention, something bad, trash, prevention,

# Figure 1

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Fear

1a) Full network 1b) Never infected Doesn't make sense Weight loss Lack of Hospit Lack of appetite Depression 1 los Weakness Something bad olutic Populati fault Malai Itcling Fores Lack of commitment Well treated at the clinic Citoos Health Something bad Rash Fever Pain Badly Death the clinic Fea Transmis PublicHealth Depression Microcephaly Disabilitie Disabilities Treatment Calamit Cc dated Lack of prevention Preventio Jointoain Can be enadicated Death Disease Disease Contagious Pain Mosquito Fe fault Prevention Cha Suffering Epidemics Microcephaly Danger Lack Malaise Mosquito Badly treated at the clinic Standing water En able popu Lack of prevention Public Health Fai Cost of treatment Stam Cutable mitmen Trash Lack of c Calemity Search for health car Hospit Aware Vulnerable population Me Empty lot 1c) Infected by Dengue or Chikungunya 1d) Infected by Zika Depression Malaise Fea Jointpain в Medicine Treat Epi tinng bad Malaise viń Hospital Lack of commitment Pre Mosquito bite Standing Weaking Standing water Lackof Can be en Public Health Microcephaly Itching Transmission Trash Mosquito Pain Population's fault Mò Chaos Disease Headache Disease Vinus ching Vaccine Dar Lack of entior Medicine

Web of meanings for Zika Virus by history of infection. Governador Valadares, Minas Gerais State, Brazil, 2016.

Source: author's elaboration based on primary survey data (Research project: Migration, Vulnerability, and Environmental Changes in the Doce River Valley, 2013-2016).

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epidemics, danger. Respondents in this cluster acknowledge that the disease will not be eradicated until the local population does their share, cleaning their houses and backyards, but also until the government takes responsibility over public places.

The *symptoms* cluster contained words related to the disease's most common symptoms: pain, malaise, weakness, fever, rash, and depression. The *media terror* cluster, except for the word microcephaly, is formed by words of low centrality in the general network, but that help to form the image of a tumultuous situation. They are: chaos, suffering, calamity, fear, medicine, disabilities, badly treated at the clinic, public health, cost of treatment, vaccine, abortion, and family. During the ZIKV outbreak, the urgent care system was overloaded and the health crisis was making headlines.

The *public health* cluster is very similar to the first, but gives extra weight to the population's lack of commitment (first word). The other words are health, awareness, symptoms, population's fault, treatment, law, and lack of treatment. The fifth cluster resembles the *media terror* cluster, but has a simpler topology since it only includes the words fear, pregnancy, and problem. From all those clusters, this is likely the one from which the only thing learned about ZIKV is its relationship with microcephaly, without any other lesson learned about preventable diseases, public health, or even people to blame. We call it *microcephaly*.

# **History of infection**

To disentangle the effects of respondents' history of infection, we separated people's evocations who have had ZIKV from those who have had other mosquito-borne disease and those who have not had any diseases transmitted by the *A. aegypti*. Then, three new networks of representations surrounding ZIKV were created (Figure 1).

## Individuals never infected (network density = 0.232; nodes = 55; edges = 344)

The web of meanings for individuals who have never been infected with any of the three infectious diseases is composed of many words and clusters, much like the analysis of the full network. The ten words with the highest level of centrality are: disease, death, weakness, mosquito, pain, prevention, something bad, lack of prevention, fever, and trash. Microcephaly has a centrality value of 31.5 from a 0 to 239.6 centrality range. Note how something bad and death, words that are unspecific and demonstrate unfamiliarity with the arbovirus, are present in this network.

# Individuals infected with Dengue and Chikungunya (network density = 0.171; nodes = 43; edges = 154)

The web of meaning becomes more restricted and structured as the history of infection increases (Figure 1). The tenth most central words are now: disease, fear, microcephaly, malaise, mosquito, health, epidemics, lack of commitment, population's fault, and medicine. Note how the words are similar to the full network's first and second clusters. Microcephaly has a betweenness centrality value of 103.0 (from a 0 to 331.4 range) and comes in the third position among the most central.

#### Individuals infected with ZIKV (network density = 0.159; nodes = 37; edges = 106)

The web of meaning of those infected with ZIKV is highly restricted. The most central words are related to the disease's symptoms, just like the cluster symptoms of the general network, with massive weight given to the word pain, which now becomes the most central word in the network (Figure 1). The other nine most central words are: disease, lack of commitment, mosquito, malaise, chaos, medical leave, rash, microcephaly (betweenness centrality of 8.4 from a 0 to 321.2 range), and itch.

As an attempt to investigate whether networks of meanings would change according to the diagnostic criterion for people with positive history of ZIKV infection, we stratified the sample (Figure 2). Note how the network of those with ZIKV diagnosed by serological tests resembles the list of symptoms released by the Brazilian Ministry of Health <sup>30</sup>. This list was comprised of fever, rash (with itch), joint pain/swelling, conjunctivitis (red eyes, conjunctival hyperemia), muscle pain, and headache. This

## Figure 2

Networks of meanings by self-reported diagnosis criterion among individuals infected by the Zika virus. Governador Valadares, Minas Gerais State, Brazil, 2016.



Source: author's elaboration based on primary survey data (Research project: *Migration, Vulnerability, and Environmental Changes in the Doce River Valley,* 2013-2016).

finding suggests that the harshest symptoms are the most salient thoughts for those infected with ZIKV. The network of clinical diagnosis, on the other hand, comprises a more diverse mix of themes, from symptoms to other public health dimensions. This goes hand in hand with the protocol utilized by the Brazilian Ministry of Health, which recommended that only more severe cases of the disease needed to undergo serology to rule out Dengue or Chikungunya infection (due to its higher mortality) <sup>7,31</sup>. Thus, in case of non-severity of symptoms, most clinical diagnoses of ZIKV could have been defined solely based on the presence of "itch". Note that besides "pain", "itch" is the only other specific symptom to appear in their network, highlighting the quality and validity of the data we are collecting.

## Discussion

Our findings suggest important heterogeneity regarding the collective representation of ZIKV. Our decomposition revealed five sub-networks of meanings, each embracing a different nuance of the epidemic: lack of social and personal responsibility, symptoms, overblown media coverage terror, public health, and microcephaly.

We find that personal involvement with ZIKV is associated with different ways to make sense of the epidemic. Using a proxy for personal involvement as history of infection, we established a model to represent the network of meanings regarding ZIKV and its associated social context, including its symptoms, fears, causes, and consequences. Using novel data on social representation of ZIKV epidemic applied to a network model for a Brazilian municipality with high prevalence of Dengue and *A. aegypti* infestation, we found evidence that history of infection and diagnostic accuracy are key to relabeling ZIKV's social representation .

Respondents who have never been infected have a much more diverse network of meanings related to the interpretation of ZIKV, one that is very similar to the configuration of the general network. Because the most important idea surrounding those representations relates to disease and death, it is possible that these maps of meanings are being shaped by the everyday messages spread by the media, which focus on preventive measures against mosquitos and the risk of microcephaly. As a result, people with no history of infection (or those with a higher likelihood of being false negatives) are more likely to think of the epidemic in a narrower way. This is a particularly interesting finding, suggesting that lay thinking is more predominant among those with less intimacy with the social object, being more easily affected by external information sources such as the media.

As individuals' history of infection evolves, they start to recognize the importance of prevention promoted by public authorities and their own share of responsibility in preventing infection. They also demonstrate more fear of getting infected and of its consequences, such as microcephaly. Their network seems more realistic as it encompasses meanings related to the symptoms, lack of personal and social responsibility, and how the disease can be eradicated. Those who have been infected with ZIKV have a more objective interpretation of the virus, especially those diagnosed through serological testing.

Given the diversity of meanings surrounding ZIKV, trying to reach the entire population using only one message or strategy might not be an effective way to reach individuals most able or ready to change. Until now, ZIKV public health campaigns have followed campaigns similar to Dengue, focusing on eliminating standing water and of mosquito breeding sites <sup>32</sup> More effective campaigns could benefit from a deeper understanding of the needs and perceptions of its intended audience(s), including their *"beliefs, current actions, and social and physical environment"* <sup>33</sup> (p. 5). Our results suggest that those who have been infected are the key actors for effective communication within the community. While people who have had Dengue can inform the general population about ways to prevent the proliferation of the *A. aegypti*, those who have been infected with ZIKV can share their experience of facing ZIKV's harsh symptoms.

One example of how this could help clarify existing campaigns in Governador Valadares is the fact that according to the most recent LIRAa report for the city, most mosquito larvae were found inside residential homes (36.7% in drains and 35.3% in water tanks on the ground). In face of these results, policymakers would erroneously think that Governador Valadares inhabitants do not know about their responsibility in preventing an epidemic. When we look at the data, however, we learn that these same spots are present in the persons' networks of meanings regarding ZIKV. Since individuals are usually well informed about what is necessary to achieve change, barriers to effective behavioral responses might lay elsewhere.

While extending the literature in multiple ways, some limitations remain. It is possible that female respondents are better informed about the virus because of its immediate impact on pregnancy. There is also evidence that those with higher socioeconomic status are better equipped than their low socioeconomic status counterparts to prevent ZIKV infection and are less vulnerable to the conditions that increase the risk of infection <sup>34</sup>. Moreover, because infestation of *A. aegypti* varies regionally across the country, the risk of infection and the likelihood of knowing someone infected likely differ geographically, with potential implications for the collective representation of the disease and for differences in behavioral responses. Future work should therefore extend this study's findings by examining how gender, geographical location, and socioeconomic status interact with the understandings of the social representation of the ZIKV epidemic.

Second, observational and laboratory studies suggest that involvement with the risk of infection changes individuals' perceptions and increases the likelihood of protective behavior <sup>35,36,37</sup>. Thus, it is likely that knowing or caring for someone who has been infected with ZIKV might change perceptions about the epidemic, regardless of their own infection status. Intensity, duration, and number of symptoms may also affect the personal experiences with the disease and must be incorporated in future analysis. We also plan to extend this analysis by accounting for exposure within households and ego-centered networks of individuals with different histories of infection. Indirect involvement may be an appropriate substitute for experience and knowledge of the disease <sup>38</sup>.

Third, the personal histories of infections we used were self-reported and stratified by different self-reported diagnostic criteria. Many factors, including hypochondria, lack of symptoms, and memory bias in patients with multiple morbidities, could affect the likelihood of false positives and false negatives. Yet, bias is more likely to remain among those with no history of infection than among those who have been infected, since all diseases here considered can be symptomless. More work is needed to understand the extent of these potential bias factors by comparing our results with the networks of meanings among patients screened at health clinics, using actual serological tests and clinical procedures conducted by trained health professionals.

Despite the limitations associated with self-reporting, gathering self-reported information on diagnosis has some advantages. First, there is a robust correlation between self-reported and biomarker-based health status, even for health indicators that are inherently more subjective <sup>24,35</sup>. Second, by stratifying the analysis by history of infection and diagnostic criterion allowed us to identify when representations were more reflective of the expected clinical symptoms of the diseases. Given the difficulty in accessing medical information, our analysis is a necessary step to shed light on the heterogeneity in which individuals signify ZIKV during an epidemic using survey data and, as such, help to improve health communication messages to reach a wider audience with more precision.

#### Contributors

G. R. Guedes participated in the conception of the study, literature review, methodological proposition, estimation of networks, analysis and interpretation of quantitative results, as well as writing of the manuscript. R. Z. Coutinho contributed in the conception of the study, literature review, data collection, coding, analysis and interpretation of qualitative data and quantitative results, as well as writing of the manuscript. L. Marteleto participated in the literature review, analysis and interpretation of quantitative results, as well as writing of the manuscript. W. H. S. Pereira and D. Duarte contributed in the methodological proposition, standardization of the data collected, estimation of networks, and reviewed the manuscript.

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# Resumo

Apesar de amplamente noticiadas pela grande mídia, muitas das consequências negativas do vírus Zika foram menos significativas em relação às previsões originais. É provável que depois de alguns meses de epidemia, a experiência pessoal com o vírus já tenha alterado a maneira individual de lidar com a doença. Este estudo explora a relação entre a exposição ao vírus Zika e as representações sociais da epidemia. Mais especificamente, analisamos se o aumento da exposição ao risco de infecção pelo vírus Zika altera as características da teia de significados em torno da epidemia. Entre agosto e novembro de 2016, foram realizadas 150 entrevistas no Município de Governador Valadares, Minas Gerais, Brasil. Com base na técnica do Teste de Associação de Palavras, os dados de citações relacionadas ao vírus Zika foram modelados através da análise de redes sociais, permitindo a caracterização da teia de significados de acordo com o nível de exposição ao risco de infecção. A análise feita aqui sugere que pessoas que nunca foram infectadas por qualquer vírus transmitido pelo Aedes aegypti têm uma representação menos completa, incorporando informações da mídia através do pensamento leigo. Ao contrário daquelas com baixos níveis de exposição, a representação social feita por pessoas infectadas com o vírus Zika está associada aos significados relacionados aos sintomas mais comuns, como dor, exantema e prurido. A experiência pessoal parece moldar a representação social da doença, aumentando o foco nas consequências mais próximas. As campanhas públicas para promover o comportamento preventivo devem levar em conta a heterogeneidade das representações dessa epidemia para poder melhorar a aderência.

Zika Vírus; Assunção de Riscos; Apoio Social

#### Resumen

A pesar de haber sido divulgado ampliamente por los medios de comunicación, muchas de las consecuencias negativas del virus del Zika han sido menos significativas de lo que se predijo originalmente. Parece que tras unos cuantos meses desde el inicio de la epidemia, la experiencia personal con el virus ha alterado la percepción personal sobre cómo lidiar con la enfermedad. Este estudio investiga la relación entre la exposición al virus Zika y la representación social de la epidemia. Más específicamente, este estudio analiza si una mayor exposición al riesgo de infección debida al Zika, modifica las características de la red de significados sobre epidemias. Entre agosto y noviembre de 2016, se realizaron 150 entrevistas en el municipio de Governador Valadares, Minas Gerais, Brasil. Basado en la Free Words Association Technique, la información sobre referencias relacionadas con el virus del Zika se modelaron mediante un análisis del entorno social, permitiendo la caracterización de la red de significados por el nivel de exposición al riesgo de la infección debida al Zika. El análisis realizado aquí sugiere que quienes nunca fueron infectados por ninguna enfermedad transmitida por el mosquito Aedes aegypti tienen una menor representación, incorporando información de los medios de comunicación, a través de un pensamiento generalista. En contraposición con quienes tuvieron un bajo nivel de exposición, la representación social de la gente infectada por Zika está asociada con significados relacionados con los síntomas más comunes, como dolor, sarpullido, y picores. La experiencia personal parece configurar la representación social de la enfermedad, aumentando centro de atención en sus consecuencias más próximas. Las campañas públicas diseñadas para fomentar comportamientos de protección deberían tener en consideración la heterogeneidad en las representaciones sociales de esta epidemia para mejorar la adhesión al tratamiento de la misma.

Virus Zika; Asunción de Riesgos; Apoyo Social

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